Spring/Summer 2005

The Michigan FAS Web



"When spider webs unite they can tie up a lion." *-African Proverb-*

MAKING A DIFFERENCE

Rob Wybrecht is someone dedicated to making a difference in the lives of individuals affected by FASD. In this article, Rob shares his experiences as an advocate for FASD awareness.

I was very young when I first learned about FAS. As I grew older, I attended FAS conferences with my parents. I would also help when my mom was coordinating FAS conferences. I really wanted to find ways I could help with prevention.

One of my first efforts started in Ann Arbor in 1998. I was passing out posters and bumper stickers at a conference for my mom and I ran out of them. I had people sign a list with their address if they wanted me to send them one. However the agency that had provided them did not intend to restock them. My mom asked me how I was going to get more. I called several places and found a company that would make them a little bit smaller and would charge \$1.00 each. I took money out of the bank and ordered 500. That was the beginning of my bumper sticker campaign.



Since then I've sold over 4,000. Recently Ann Streissguth took some of them to France with

her, and when my mom went to Africa she saw one there. I sell them at cost, not for profit, and I found when I placed a larger order, I get a better price. The bumper stickers are available for 50 cents a piece.

Another important project I've been involved with was my role in the video *Students Like Me*. It was made here in Michigan, and was created to help elementary school teachers understand how to help children with FASD's. I shared information on what was helpful to me when going through school.

I've become very active in speaking at conferences on what it's like living with FAS and how difficult it was in school and at work. As a member of a national group of adults with disabilities, I helped develop a peer training project to help people understand their rights and responsibilities if stopped or questioned by the police. It is called *Equal Justice*. I have done this presentation several times in Michigan, once in the state of Washington and soon I will present it at a conference in Kentucky.

One of my goals for the future is to help employers understand what it's like to have an FASD, what problems they might encounter and how to solve those problems.

If you are interested in more information about any of the initiatives, please email robw995@aol.com

YOU NEVER KNOW WHAT TURNS YOUR LIFE MAY TAKE LYNN SEELY

Thirteen years ago my now ex-husband and I adopted three of our grandchildren. The two oldest have Fetal Alcohol Syndrome Disorders. The youngest has learning disabilities.

When my daughter was 16 years old, she believed as a lot of people do - "It won't happen to me." She liked to party; she loved her boyfriend. She also knew that I didn't know anything—after all I was just a stupid parent who nags.

Then all of a sudden her life changed. Things got out of hand. It's not easy being a teenager, and it's even harder to be a parent. For us, we were devastated as we watched alcohol take over my daughter and her husband. The ravages of its effects on their lives were marking our oldest grandchild. It created havoc for him daily. Two months after the birth of our second grandchild, a darling little girl, we knew we had to step in or we would lose our grandchildren.

This certainly wasn't what I thought my life would be at the age of 40. I thought I would be done raising kids, able to golf, work and golf,



and golf some more. Those were my plans for the ages of 40-50. Instead I found myself starting out on the greatest challenge of my life and during this time of transition, my daughter became pregnant with her third child. He's a charming boy with a heart that just envelops you.

The oldest child had rages when he came to live with us. I excused them, thinking it was because he had lost his mom and dad. Almost everyday I would have to put him in his room

and close the gate. I would sit in the hallway listening to him rage. He would call me names that you would never think a two-year-old would know. Tonka Trucks became weapons as he hurled them at me all the while he was screaming. My heart would rip watching this tiny boy venting so much rage. I was sure he wouldn't get through it. It was normal for this to last 45 minutes. I would watch as he would finally fall into a heap and his body would shudder with the aftershocks of his rage. It would be at this point that I would finally be able to hold him and talk to him. He would cling to me, sobbing. I didn't know what was wrong with him. Counselors said it was separation anxiety. So I thought with a little love and time he would be OK. How I wish that would have been true.

As the oldest entered school, his rages made it so that other children would look at him as weird, and eventually no one wanted to be his friend. Teachers said he didn't pay attention and that he was trouble. They said he could do better if he would just try. So the label of Attention Deficit Hyperactivity Disorder (ADHD) was attached to him. Soon everyone thought there was more to him than just the ADHD and the letters of ODD (Oppositional Defiant Disorder) were added and soon to follow was Conduct Disorder (CD). When that range of alphabet soup couldn't describe him, they decided to add depression and impulse disorder to the list. Teachers would groan when they heard they were to have him in their classes, and kids would laugh at the child who was so different.

Our granddaughter was the sweetheart of the class, but all mourned that she would have to attend special education. But don't grieve for her, she was the lucky one. She was diagnosed as FAE (Fetal Alcohol Effects) when she was seven years old. Because of the difference in the way our oldest and she acted, I wouldn't

LIFE TURNS CONT...

realize for a long time that he also had an FASD.

Our oldest grandson went through many years of getting suspended day after day. Some teachers would get a glimpse of the deeper child, his humor, his ability to show great mercy to those who had no one else to give it to them, but those days were few and far between. For the most part he would be a thorn to the teachers and school and, in the end, he was tossed into alternative education and, eventually, juvenile detention.

He just doesn't understand cause and effect, and his lies serve to compound his problems. You see, he would do the same thing over and over and just didn't learn that it would be wrong every time. After all he didn't leave at 1:00 AM this time. It was 1:30 AM when he left. I had told him he couldn't leave the house at 1:00 AM. Well it wasn't 1:00 AM, so why all the trouble? He would beat his little brother up all the time, as he would his brother's friends. Now the youngest is left without friends because they are all scared of his big brother. But still, sometimes he would amaze you with stories he wrote or poems that would let you see into his private hell. Those are the times that make it so you can get through the other times.

I lived a life of not being able to go to work. The oldest just couldn't handle the knowledge that I was not at home, and soon the phone calls to work would end the job. I couldn't leave the house without having him with me; there was no one to leave him with. No one else could handle the problems and the stress. No one invited us to dinner. No one dropped in because it was impossible to have a visit without something drastic interrupting us.

I want to make sure people know all of this is preventable. I'm finding opportunities to share this information with others. My message is simple - If you are having sexual relations, don't drink! - not one beer, a glass of wine, even cough medicine with alcohol content. Life takes turns you can't imagine when people drink and have sex. Remember, accidental pregnancy happens all the time. By the time you find out you are pregnant the damage could already have been done, and the results are something your child may end up having to live with for the rest of his life.

The consequences of FASD will forever change your life. You could have to be on call 30 hours a day, every day. Your life could be filled with psychological therapists. doctors. advocating, and sleepless nights for about 30 years. People will be sure you don't discipline your child. You may find your family shunned from things as simple as play-dates possibly all the way to holiday family gatherings. The stress will live with you day and night. You will either find more strength within yourself than you thought possible, or you will end up with someone else raising your child. Sound harsh? It is. But those are the realities you will live with. You will hear from some people "I drank when I was pregnant and my child is fine." Well they were one of the lucky ones. It doesn't always happen. Are you really willing to find out if your child will be one of them?

I hope you will join me in efforts to share this important message.

If you're pregnant don't drink.
If you drink, don't get pregnant.

FREE FASD PREVENTION VIDEO

A new video, "Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders," features a series of women who tell poignant and memorable stories about alcohol use during pregnancy and its effect on their children. Their experiences are supported by expert clinicians and researchers who talk about disabilities associated with FASD and evaluation and intervention services.

The hour-long video is divided into two half-hour segments to allow discussion time within treatment sessions. The video package includes a brochure for counselors or facilitators to read in preparing to show and talk about the video, and a second brochure to distribute to women to keep as a reference after viewing and discussing the video.

For a **free** copy of "Recovering Hope," contact SAMHSA's National Clearinghouse for Alcohol and Drug Information (NCADI) at 800-729-6686 or visit www.ncadi.samhsa.gov. The product inventory number is CR69.

ELECTRONIC ACCESS TO THE NEWSLETTER

Thank you for responding to the newsletter address update request that was mailed this spring. We were able to correct a lot of information.

If you are interested in receiving the newsletter by email, please send a message to sarah.bobo@kentcounty.org. You will be able to receive electronic versions of the newsletter.

If you are interested in any of the previous editions of the newsletter, they can be accessed from the State's FAS webpage at www.michigan.gov/fas

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